## Parent Action Council January 12, 2006 Meeting Minutes

In June 2005, the Arizona Department of Health Services, Office for Children with Special Health Care Needs was awarded a three year grant entitled, "Integrated Services for Children with Special Health Care Needs, Priority #5: The President's New Freedom Initiative: State Implementation Grants for Integrated Community Systems for Children with Special Health Care Needs." The Grant was awarded by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB). The Grant proposes the creation of the newly formed Arizona Integrated Task Force and eight (8) committees comprised of stakeholders from governmental and state agencies, local, and community level providers, parents, children and youth with special health care needs (CYSHCN), and their families. The Parent Action Council has been formed for this purpose and held its inaugural meeting on January 12, 2006.

**Parent Action** 

**Council Purpose:** Provide a single informational resource about all activities involving parents throughout the state, and to facilitate

cross training, and mentoring of all parents. The Council will review local activities and make recommendations to the

Task Force.

**Facilitator:** Marta Urbina

Health Program Manager III

AZ Dept. of Health Services-Office for Children with Special Health Care Needs

**Principle Investigator:** Jacquilyn Kay Cox, PhD

Section Manager-Data, Planning and Evaluation

AZ Dept. of Health Services - Office of Children with Special Health Care Needs

**Attendees:** Barbara Bower - ACTION Partnership for People with Special Needs

Jacquilyn Kay Cox, PhD - AZ Department of Health Services/OCSHCN

Trini Ferra - Parent Leader

Linda Hamman - AZ Department of Health Services/OCSHCN

Gretchen N. Jacobs - Greenberg Traurig, LLP

Denise Jones - Parent Leader

Ginny Love - ACTION Partnership for People with Special Needs

Renee Nichols - Page Partnership for People with Special Needs (via video)

Kim Stamper - Tri-City Partnership for Special Children and Families

Linda B. Strayer - Tucson Community A.C.T.I.O.N. Team

## Mark Trombino - Parent Leader Marta Urbina - AZ Department of Health Services/OCSHCN

SPEAKER	DISCUSSION	ACTION ITEMS
Marta Urbina, ADHS- OCSHCN	Welcome. Our office would like to thank you for your participation on the Integrated Services Grant Parent Action Council. We want to take some time to get to know one another and learn about the grant. I want to introduce Jacquilyn Cox, from our office. She is Principle Investigator for the Arizona Integrated Services Grant and she will educate, inform and answer any questions you may have. Another strategy we hope to use is to video tape Jackie's presentation and have this as a resource for your use.  There is alot of information that will be shared today, and it will be a resource that you can use again to refresh yourselves with the information. It will be helpful to those participants that didn't have a chance to participate today (Art Gode from Kingman and Twila Pochema from the Hopi Nation). I would like for this meeting to be helpful to all. Renee Nichols has joined us through our tele-conferencing and we have to be mindful that we have a Flagstaff videoconference feed. We also thank Northern Arizona Regional Behavorial Health Administration (NARBHA) for the telehealth connection.  Please take some time to review the resources in front of you. Also make sure that your contact information is correct. We will share much of our information through email and the Internet for this council	Marta suggested that a video of Dr. Cox's Grant Overview presentation be video taped for future reference and use.
Marta Urbina	Please let's take a moment for introductions around the table.	
Council Members	Each attending member participant introduced themselves to the group and provided a short background of their involvement with communities and children with special health care needs.	
	Marta Urbina, ADHS- OCSHCN  Marta Urbina Council	Marta Urbina, ADHS- OCSHCN  Welcome. Our office would like to thank you for your participation on the Integrated Services Grant Parent Action Council. We want to take some time to get to know one another and learn about the grant. I want to introduce Jacquilyn Cox, from our office. She is Principle Investigator for the Arizona Integrated Services Grant and she will educate, inform and answer any questions you may have. Another strategy we hope to use is to video tape Jackie's presentation and have this as a resource for your use.  There is alot of information that will be shared today, and it will be a resource that you can use again to refresh yourselves with the information. It will be helpful to those participants that didn't have a chance to participate today (Art Gode from Kingman and Twila Pochema from the Hopi Nation). I would like for this meeting to be helpful to all. Renee Nichols has joined us through our tele-conferencing and we have to be mindful that we have a Flagstaff videoconference feed. We also thank Northern Arizona Regional Behavorial Health Administration (NARBHA) for the telehealth connection.  Please take some time to review the resources in front of you. Also make sure that your contact information is correct. We will share much of our information through email and the Internet for this council.  Marta Urbina Please let's take a moment for introductions around the table. Each attending member participant introduced themselves to the group and provided a short background of their involvement with

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
Introductions (con't)	Marta Urbina	Thank you all. For background on what Linda and I am involved	
		with; we have 11 parent-led action teams and are targeting 2	
		more for this year.	
		If we can quickly review some of the resources in front of you.	
		We have posters for you and sign in sheets are going around. In	
		your binder, you will find under Divider 1 of the Table of	
		Contents is the List of Participants. Please take a few moments	
		to make sure our information on you is correct. You will also	
		find the other committees that have formed and their Participants	
		Lists along with the Task Force partners. That is the contact information for those work groups under the Integrated Services	
		Grant. And we want to be respectful of your time and the	
		telehealth connection and will end promptly at 3 pm or before.	
		Divider 3 has the resource information for the presentation today.	
		Feel free to take notes. Divider 4 provides resource information	
		on the Task Force and the Committee Tasks Overview. Multiple pages that identify the purpose of each of the committees, and the	
		required activities under the grant. The multi colored handout	
		(Divider 4 of binder) describes our partnership with Maternal	
		Child Health Bureau (MCHB). And you will hear a lot about	
		Performance Measures, as you look around the room, you can see	
		those posters. Divider 5 is inclusive of the Project Abstract and	
		Narrative of the Integrated Services Grant. We have a goody bag	
		in the back of the binder. And finally, the ISG Survey in the flap	
		of your book, please fill that out and send it back to Jackie. If you have a business card from your work with families and	
		business entities, we would like for you to leave one with us	
		today.	
	Denise Jones	Mentioned that she receives the Raising Special Kids monthly	
		newsletter and they had recent special section on the Integrated	
		Services Grant and it was very informative.	

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Overview of the	Jacquilyn Kay	Let me explain the significance of the flashlight. When we were	
<b>Integrated Services</b>	Cox, PhD;	trying to come up with an overview of what to put on the cover,	
Grant	ADHS-	the Office Chief in Women's and Children's said that "you have	
	OCSHCN	a whole map of Arizona and all of these committees and	
		participants are the flashlights". So carry it on your keychain to	
		remind you that <i>you</i> are one of our flashlights.	
		We will go over the philosophy of integration, various	
		components of the grant, and then some of the data projects and	
		the outcomes. Integration is, if you follow what's going on with	
		the MCHB, the great theme. They want to avoid duplication, but	
		more than that, this particular grant focuses on integrating	
		services, and they are integrated at the community level. This	
		particular committee is very important because you actually	
		represent the town and cities where that integration should occur.	
		Many of the other committees have a heavy representation of	
		agencies and providers. This committee is our grass roots.	
		The unifying themes, if you look around the room, you will see	
		the 6 Performance Measures that the MCHB has promulgated in	
		the last few years. They are meant to capture some of the critical	
		elements of delivering service, integrating families and	
		communities, and promoting families as decision makers.	
		Every 5 years, our office does a statewide Needs Assessment and	
		based on that, we determine the priority areas to work on to	
		address these performance measures. We completed the Needs	
		Assessment for 2005 and submitted it in July. Every year for the	
		next 5 years, we evaluate what we are doing as we address each	
		of the priority need and the six performance measures. These	
		Measures direct many of the activities that we are involved in.	
		Obviously, Community Development with Community Action	
		Teams are part of parents as decision makers and parents as	
		partners in the community based activities.	

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Overview of Grant (con't)	Dr. Cox	We have observed what is going on in Arizona now and tried to find elements that would fit an integration model. We think we have a model now that may be implemented in the next few months, that would be "one stop shopping"-you apply for this application and it is spun off to other agencies so people are not having to fill out multiple forms. There is an on-going project at Mountain Park Community Health Center in metro Phoenix. They have a grant that is looking at integrating behavioral health services into a primary care setting.  Also, the Early Childhood Comprehensive Systems grant was awarded to the Office for Women and Children. They are the department that funds the school readiness board and they do a lot of things around literacy for children (i.e.: promote reading program at the primary care physician's office).  The Health Query is a project by ASU's College of Business. They are trying to create a super database that will take all the data that different agencies hold and have one stop shopping on health data. AZ Department of Education also has the Transition Leadership Team that crosses many agencies and we are actively involved in that. This program focuses on when adolescents transition out of the secondary education system. And the 211 program that AHCCCS and ADHS is trying to coordinate to put all resources of community information and referral at one number.  The Integrated Task Force is a large part of the Arizona Integrated Services Grant. What we envisioned was a group that represented the leadership of Arizona in areas of healthcare, education, social services, professional organizations, and families. Out of that, many action committees are formed (which this is one), to come up with a plan to submit to the Governor.	ACITORITEMS
		This is where the Parent Action Council fits in.	

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Overview of Grant	Dr. Cox	The second part of the grant is the Medical Home Project. We	
(con't)		are going to establish 4 sites, 2 pediatric clinics and 2 school-	
		based clinics. We will do a variety of activities from providing	
		screening to care management. Then we will look at the different	
		outcomes between the two settings.	
		The Integrated Task Force is the umbrella organization to provide	
		this statewide forum. Its main goal for the next 3 years is to	
		focus on CYSHCN and report to the Governor with specific	
		recommendations that will facilitate the delivery of health care	
		and integration of services for our children with special health	
		care needs.	
		We have our own website. If you have any questions, please	
		visit the website. www.azis.gov We are encouraging cross-	
		posting on this website to facilitate communication.	
		Dr. Cox gave a brief summary of the sub-committees under the	
		Integrated Service Grant. The Quality Improvement, Parent	
		Council, and Youth Council are three committees authorized as	
		mandatory under the grant. Those committees and the other sub-	
		committees formed under the grant are further discussed in your	
		binder under Table of Contents Tab 4-Resources.	
		We started this process last November. We brought about 50	
		people together and asked them about activities that were	
		currently going on in the state and communities. We asked for	
		suggestions on improvement, the barriers they encountered, and	
		what needed to be done. Many of the people identified the	
		concept of Medical Home, but there was no baseline competency	
		to measure the activities. Many advocacy groups are out there	
		educating around Medical Home but many critical concepts of	
		implementation, delivery and measurement are not addressed. So	
		the message has to be systematically promulgated in the	
		community so we can develop a baseline competency.	
		We are also hoping to utilize the ADHS e-learning system. A	
		computer based education system that allows you to deliver	

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Overview of Grant	Dr. Cox	information, and attach to that is a chat room where people can	
(con't)		go in and share their thoughts and ideas on topics. It also gives	
		people a way to communicate long distance. We will be bringing	
		up many learning modules through the e-learning system.	
		The Specialty Services Committee will be coordinating people	
		and sites participating in the Tele-health system. Our Telehealth	
		system goes through the U of A "bridge" and that can cause some	
		difficulty at times but we are hoping that the Specialty Services	
		Committee can help smooth the way for better tele-health usage.	
		The Parent Action Council. This group is one that will grow in	
		size as you reach out to the community and other parent	
		advocacy groups. The Youth Council will hopefully start next	
		month. They will develop the Community Adolescent Health	
		Profiles by going out in the community and looking at what the	
		health of adolescents are the community. They will also serve as	
		a clearinghouse for information on transition. We hope that the	
		Youth Council will utilize the e-learning system for transition	
		modules.	
		The Community Development Initiative will give updates on	
		what is going on at the community development level, and the	
		methods of sustainability on some of those activities.	
		The question for Medical Home is coming from physicians	
		themselves. They say the reason that they do not have a medical	
		home is that there is no way to bill for the extra services that are	
		necessary in the medical home to make the care continuously	
		available, and then to outreach into other areas. So we said, if we	
		provided the person on the front end that identified the needs of	
		children (that would be our screener); then, would that assist you	
		in better providing more comprehensive care? If we put a care	
		coordinator in that practice, would that care provider facilitate	
		other types of services being integrated into that practice?	
		Screening is not just developmental. Screeners will also look at	
		dental, mental health, adolescent issues related to transition, and	
		other factors identified.	

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Overview of Grant	Dr. Cox	The data projects we have going on now is the Survey in the back	
(con't)		of your book. Please answer those questions as much as you	
		have knowledge on the topics. We give these completed surveys	
		to the Task Force and they develop a report which is accessible	
		on the website.	
		One of the questions most revealing was "what would they see as	
		a task that would be done around integration". From a practical	
		approach to a wishful approach. The most common was the	
		universal application. But also to integrate primary and	
		behavioral health, and to integrate specialty and primary care.	
		They seem to describe a Medical Home setting when they	
		explain integration of services.	
	Gretchen	What is a medical home?	
	Jacobs		
	Marta Urbina	It is basically, a concept of providing care. That the care is	
		coordinated, continuous, and available. All the ideas and	
		characteristics that evolve around this. 24/7 care, better	
		connection to a doctor, family centered, and culturally competent.	
		The type of care that provides resources to educate and inform	
		families. It describes the characteristics of the medical practices	
		that are based on knowledge and resources, not so fragmented or	
		specialized. It is very supportive to family.	
	Dr. Cox	What you see with children with special health care needs is that	
		many families are reliant on specialists and they cycle in a	
		specialized setting. There may not be enough attendance to	
		preventative medicine and education. Normal, developmental,	
	T ' 1 TT	preventative medicine is not addressed or it is overlooked.	
	Linda Hamman	How many sitting here believe they have a medical home setting?	
		The council discussed how the medical home, as it stands	
		currently, could actually be the mother or the father. Ms.	
		Stamper made point of the fact that having a child with special	
		needs means that the parent gets involved with so many agencies	

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Overview of Grant		and people, from the school nurse, the school administration, the	
(con't)		primary care doctors, even the department of health services, so it	
		would seem that, based on the information the parents compile,	
		they do have a medical home and not even realize it.	
	Dr. Cox	When we started looking at medical home and the philosophy,	
		we discovered "school based clinics". When we look at these,	
		the primary groups that they serve are the people that are	
		typically not served in the health care system. They are the	
		"undocumenteds", the under-served, or the people with limited	
		access to any type of health service. They find a base where they	
		feel secure and then the whole family comes in. You have made	
		it safe for a much neglected group to get health care. And these	
		places are booming, while seemingly flying under the radar of the	
		established health institutions.	
	Denise Jones	In my case, for example, physical therapy for my daughter. One	
		has to go through so much information and "hoops". From	
		primary insurance providers to billing and denials. I am on the	
		phone constantly trying to find the right people. Where is a	
		support group, no matter if a child is diagnosed or not? There's	
		an average of 2 hours on the phone. So much legwork that the	
		average person will give up.	
	Dr. Cox	Dr. Cox asked what would be the way to improve that resource	
		base and communication. Is that educating people? How do you	
		create the awareness for that? Dr. Cox reiterated that the people	
		in the health care delivery system are not educated on support	
		groups or outreach. 211 and the web-based e-learning module	
		may be able to help address combining resources for easier	
		access to needed information.	
		Ms. Jones reiterated that she liked idea of the "one stop	
		shopping" or one place and having a screener, or to get a referral.	
		People that are specifically looking, for example, an advocate.	
		Make it one to two steps as opposed to 20 or 30.	

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Overview of Grant	Dr. Cox	We can hopefully build some of this into the 211 Program. Our	
(con't)		website <u>www.azis.gov</u> is a very useful tool as well. Each sub-	
		committee formed under the Integrated Services Grant will have	
		their action plans and project abstracts submitted to the Task	
		Force, and the Task Force will submit a final report with their recommendations to the Governor. The Task Force meets	
		quarterly and all committees (except this Parent Action Council)	
		will meet monthly.	
		We are haping in the winter 2006 or early enring 2007 to pull all	
		We are hoping in the winter 2006 or early spring 2007, to pull all the committees together and have a mini-conference.	
	Discussion	There was group discussion about recruiting and/or inviting for	Any parents wishing to become
	Discussion	the Parent Action Council to increase the number in the group.	involved in the Parent Action
		the rate in rection countries in the group.	Council can contact Marta Urbina
		Dr. Cox also reiterated that the Youth Council was trying to	at ADHS. (602-364-3301)
		recruit youth to participate. She said that she would like the	urbinam@azdhs.gov
		teenage group well represented. Also adults, who were special	
		needs children that became successful in the community, to	Dr. Cox reminded the group to use
		mentor the youth.	the "Project Abstract Form" to
			suggest any new projects to be
		A question was raised as to the website and the specific	submitted to the Task Force.
		information and/or resources that may be available on it, and is it	
		interactive at this point. Dr. Cox stated that the each committee meeting minutes, action plans, and progress reports are posted on	
		the website.	
		Marta explained how tele-health facilities would help encourage	
		parents to participate.	
		Ms. Jill Kipnes entered the meeting and gave an update on the	Ms. Kipnes informed the group
		specifics of the website. That it would be a learning management	that they are defining the linkages
		tool with teaching modules. The website will be interactive with	now and will know more in a
		discussion boards for 2-way communication. It will also list	couple months.
		resource, action plans, project abstracts, and other general	

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		information on the progress of the sub-committees, the Task	Contact people, with their email
		Force, and grant activities.	address, for each committee will
			be given on the Participant Lists.
	Marta Urbina	Marta stated that the Council members are resources in the	
		community, and should utilize the existing relationships to recruit	
		more family members. We know that the Council is a core group	
		that will work with the Task Force, but <i>you</i> want to use us as a	
		vehicle too.	
		A question was raised as to where to start if someone saw the	Dr. Cox stated that any concern
		need for a change that involved more than one committee.	could be emailed to her as that
			could develop into an agency
		Marta stated that if anyone had an improvement they believed in,	project recommendation to the
		the Council would want to address it and solve the problems, to	Task Force.
		have all ideas at one time for recommendation to the Task Force.	
		This leads us to the Tasks of the Parent Action Council.	
Tasks of the Parent	Marta Urbina	The structure of the Parent Action Council is to meet quarterly	
<b>Action Council</b>		and then have call conferencing in the off months. When we	
		developed the structure, we looked at the travel and money	
		barriers to participation. We can increase family participation	
		through entities like NARBHA in which we use our tele-health	
		resources. We want to organize ourselves in such a way as to	
		make viable recommendations to the Task Force.	
		If you go to Section 4 in your binder, you will find the Task	
		Force and Committee Tasks Overview. We have a replacement	
		page on page 4 so I will hand the new pages out.	
		With the Parent Action Council, we want to successfully report to	
		the other committees and Task Force what it is we are doing,	
		what it is we decided to do, and by when.	
		The Parent Action Council already has one task. To "review	Task: Parent Action Council will
		local activities and make recommendations to the Task Force".	review local activities and make a
		This involves the topics of parents as decision makers, ease of	recommendation(s) to the Task

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Tasks of the Parent		use, medical home, and transition. This is the framework and we	Force. Refer to Committee Goals
Action Council (con't)		can always expand on it. Under outcome and performance	handout for the specific
		measures (referring to Committee handout-Goals), this task	outcome/performance measure(s)
		would be responsive to (#1 outcome) a percent of MCHB funded	that will be affected.
		programs that are sustained in the community after the federal	
		grant period is completed. Ms. Urbina asked Dr. Cox to explain	
		a bit further.	
		Dr. Cox stated that it mainly had to do with sustainability of	
		whatever process or action is taken.	
		There was a question as to what was meant by "local activities".	Local activities at the community
			level. Either in community
			development teams or other
			activities you may be involved
			with.
	Dr. Cox	Explained the MCHB Title V performance measures unique to	
		the Parent Action Council (Section 4 of binder). She stated that she streamlined the measures for each committee, and the	
		particular MCHB performance measure that applies to the Parent	
		Action Council is page one of one (4 <sup>th</sup> page after Title V	
		Performance Measures title page in Section 4 of the binder)	
		"Using a scale of 0-3, please rate the degree to which our grant	
		program has included families into their program and planning	
		activities." That is a standard MCHB performance measure. We	
		will be able to measure and satisfy that performance measure	
		based upon the activities of each committee or council.	
		There are performance measures that apply to other committees,	
		but the ones that are particular to family or communities were	
		pulled for inclusion as the outcome measures for this committee	
		(Goals handout) One of the outcome measures that they want us	
		to specifically track is- if this grant is funding a project in the	
		community (and there are dollars in the grant to support the	

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Tasks of the Parent	Dr. Cox	development of two new community teams), then we need to	
Action Council (con't)		report on what the sustainability plans are for that team when the	
		grant period ends. So as we expand and build, we need to keep	
		track of what we are doing.	
		Another Depart Action Council outcome messure is (mass 2 of 2	
		Another Parent Action Council outcome measure is (page 2 of 3 of Title V Performance Measures in Section 4 and #2 on the	
		Goals handout) "the degree to which MCHB supported programs	
		that ensured family participation in program and policy	
		activities". They want us to report on how many family members	
		are participating in community task forces, where are they	
		coming from, how many people are receiving training, mentoring	
		or reimbursement. So from now on, we will gather that	
		information. Also, the financing of travel, respite care, lodging	
		etc. for the parent group as needed, and there is money in the	
		grant to fund this. We also need to see if we attracted parents	
		that needed assistance or attracted parents that are not in need.	
		Dr. Cox stated that family members also work with their	
		professional partners to assist in training. We would want to	
		track that too. How many parents are participating in professional training or will assist in training. Some of the	
		community teams already have these activities going on. We	
		would like to help them expand and build so we will need to	
		develop a mechanism for you to report that into us.	
	Linda Strayer	If we have trainings, whom are we running these trainings by?	
		Ms. Urbina stated that we don't approve them but to document	
		that the activities occurred. Gathering activities of how we	
		incorporated families into training activities in general. We want	
		to know how families are training professionals. We want to	
		gather what topical <i>areas</i> the families are training on as well. I	
		am already thinking a little form.	

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		Dr. Cox stated that there does need to be a form. We want to	A training activity form to
		document parent-driven training as much as possible.	document parent-driven training was suggested.
Tasks of the Parent Action Council (con't)	Marta Urbina	How does this information build the overall picture? How does what we learn and gather from these activities, how does it contribute?	
		Dr. Cox stated that it depends on what it is. But for example, when there is a need for some kind of training of professionals in the community, and because of what families are already doing, that training occurred. So you identified the need and filled the need at the same time. The community then sees the parents as a resource and <i>this</i> shows the strength of parents in community development and involvement.	
	Barbara Bower	How are we going to reach the parents who are not involved? Is there a statewide publication for parents of children with special needs where we can say "parents, please contact"? Marta explained that Tucson is a good example. A one-page survey as to "what is working in Tucson", as to opposed to what was not working. The Tucson Action Team concentrated on the areas of recreation, in-home care, and doctors. There was also information as to who to contact if people wanted to learn more. It soon became a tool to learn what the families knew. Then they further utilized a portion of the survey as a marketing tool for marketing and outreach to more families.  Ms. Strayer mentioned that if parents don't want to get a hold of you right away, they won't. But this does not mean they will not contact you 6 months down the road. So we keep disbursing the	
		information but until they are ready, they won't come to you.  There was discussion on how the education system (paraprofessionals) and family focused groups can develop partnerships to further initiatives, for example, for developmental	

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		pre-school. Ms. Love mentioned that there are family focused	
		groups that do good work. Ms Urbina said it would contribute	
		immensely if, where appropriate, the council could engage their school districts in areas. This can help family focus groups	
		develop a new skill-base. Leadership skills and mentoring.	
		develop a new skin base. Leadersing skins and menoring.	
Tasks of the Parent	Gretchen	Is it possible to obtain a diskette or CD that is informational?	CD or informational packets from
Action Council (con't)	Jacobs	Perhaps from an organization, for example, dealing with autism.	organizations that have resource
		A listing of places where they can go dependent on the diagnosis	listings for parents to utilize.
		such as spina bifada or autism. "Here's what you begin to do and	
		here's the organizations you can go to". Get information together for each group such as spina bifada. They can reference it for	
		information on treatments, different types of proven treatments,	
		advocacy, and support groups.	
		and country, and copport groups.	
		Dr. Cox stated that she believed Raising Special Kids was talking	Dr. Cox will give Wendy Benz,
		about this. My contact there is Wendy Benz so I will have her	Raising Special Kids information
		contact you. I believe that is a good activity and it would be nice	for contact to Ms. Jacobs
	M 1 T 1 '	to see it parent-driven.	
	Mark Trambino	As we put our tasks together and outline this for the next three years, what about other states? What have other states done that	
		worked well or did not work well? As we put these strategies	
		together, we could benchmark off them.	
		There was discussion as to other states and where they were	Benchmark off other states.
		currently at, with regards to disbursing informational services out	MCHB website resource page
		to parents of children with special health care needs.	gives "best practices" from other
			states. NIH website.
		Dr. Cox stated that there is community development family	
		involvement at a national level but are the states doing it	
		Ms. Urbina said that on the national level, it used to be the Pacer	
		Center. They keep the polls on all the parent training and	
		information centers.	

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
MEETING ITEM Tasks of the Parent Action Council (con't)	Discussion	Dr. Cox stated that there may not be states doing what we specifically are talking about. It's a big task. We should begin with, at the least, a list of resources of where one would go. She mentioned that MCHB has a resource page that may pull out "best practices" from other states.  Ms. Hamman mentioned NIH where they have topic-specific linkages direct from their web page and they had all the latest information on different topics.  Would the specific advocacy groups be a resource? Are they pulling from other states? Ms. Bower said that the Spina Bifada Association is nationwide and has an annual conference. All the CRS doctors and therapists are there with local spina bifada advocates.  There was further discussion on how families can get to various "best practices" information and utilize it. It was stated that highly motivated parents of children with special health care needs assume so many roles, from care coordinator to research analyst. The survival of the family is so dependent on the correct information being given, but most parents don't know where to start when a diagnosis is given on their child.  Ms Stamper stated that a beginning point would be education of the parents. Many parents don't understand but if they had a place to go to gather information, they would become aware.  Dr. Cox said that many times, in Arizona, a mother of a special needs child is negatively coordinated based on lower education or	ACTION ITEMS

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
		Ms. Jones reiterated that the parents are all alone. They want to reach out but there's no connection to anything. They become overwhelmed and frustrated so the focus could be simply on the	Focus on how to reach parents with informational resources.
		way to reach them.	
Tasks of the Parent Action Council (con't)	Marta Urbina	Marta stated putting the resources into action is a good idea. We have the expectation to do something with the resources, to give more options to parents. There is a lot of word-of-mouth going around on various topics in all communities, but we need to give a resource that can be read and understood.	
		So we need to come up with some tasks that will help this Council start reaching out.	
		Dr. Cox stated that the timeline is tight but if this group could come up with a mechanism to involve families at the community level, which could be a starting point. The pool of people is ready but there is no mechanism in place that is hands-on and diversified enough to fill the need that is out there. Valuable health care information based on the delivery system. How would you make it culturally appropriate, and that is <i>not</i> just color and origin.	Involve families at the community level.
	Marta Urbina	So let's finish the outcome measures and then come up with some tasks. We covered cultural competency.	
	Dr. Cox	Dr. Cox offered that when we did the needs assessment, we are required to have active input from the communities and families we serve. We have yet come up with a mechanism to make that happen. If this group could define a mechanism that we could implement so that when we do our response to the block grant, that parents, in various communities, would have the opportunity to respond to it and give input would be wonderful. That touches on the program planning, service delivery, and evaluation processes (of #3). It is always in the plan to involve families, communities, and focus groups but there has never been a mechanism. We have not defined "how to get community	

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
		effort". If you go out to your community, find a mechanism, test	
		it, and utilize it when needed; the whole world would be grateful.	
To be eat a December	M . III.	And keep in mind, with #3, the whole thrust is to get diversity.	
Tasks of the Parent Action Council (con't)	Marta Urbina	Is that something the group can work on? To develop a process or mechanism.	
Action Council (con t)		of mechanism.	
		Ms. Stamper stated that she needs a starting place from all that has been discussed.	
		Dr. Cox stated to generate a list and prioritize it. Maybe during the next two years, the group can only do two of the priorities. That is not a problem. The list doesn't go away. As it is defined now, your task is to "review local activities and make recommendations to the Task Force". Start with that, it is a given.	
		Ms. Stamper asked that when we leave today, what do you want each of us to be responsible for.	
		Discussion ensued regarding what priorities may be listed. Identified topics were increase the number of people on the Parent Action Council. Ms. Urbina stated that a small profile of all the members would be in order. A snapshot of what you are	Increase the number of people on the Parent Action Council. Set a target number.
		involved with, etc. So we can establish what is missing, what we do not have in the group. Identify what we have so we know where to go. From geographic to personal areas.	Council members will do a short self-profile, including a family profile, for submission to Ms. Urbina by January 19 <sup>th</sup> .
		Ms. Strayer stated that we could also list "potential" people that we already established a relationship with, or an agency worked with, that may be used for resource information.	
		The outline given:	
		1) Increase number of members in Council	
		Include factors – diversity, profile of current members,	
		geographic, age, disability-special needs agencies used	

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
		2) Increase communication – develop email list	
		3) Potential members – parent or youth	
	Marta Urbina	Ms. Urbina reviewed the scheduled meetings for the Parent	Monthly conference calls will be
		Action Council. The Council will meet quarterly. The Council	scheduled between meetings
		discussed the schedule of meetings and who may be earmarked to	Conference call scheduled for
		join us through tele-conferencing.	February 23, 2006 for one hour
			9:30am to 10:30am
		Ms Urbina reminded all the Council members to complete the	
		Evaluation Form that was handed out in their meeting packet.	
		She thanked all the parents for their participation and looked	
		forward to a successful collaboration into the future.	
<b>Next Meeting</b>		April 13, 2006 12noon to 3pm/Room 345A -ADHS Bldg.	